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Misinformation is publicized as the next big public health crisis. Its exploitative nature allows it to both embed in seemingly legitimate facets of public discourse and disrupt public health initiatives. It collectively influences individual health decisions through a strategy of personal, message-oriented and emotional narrative. Utilizing the lens of vaccines, specifically the controversy surrounding the HPV vaccine in North Carolina, this study illuminates on health misinformation as an instigator of public conversation, vaccine hesitancy, and its subversion of evidence-based authority. This study provides a comparative analysis of both public and legislative perspectives, revealing a mismatch between the information needs of the public and the information written into state vaccine law. The findings offer a preliminary step towards understanding how misinformation persists in the public sphere and affords insights into how public health can evolve to better encourage autonomous health decision-making, minimizing the influence misinformation holds over its audience.

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BEWITCHED, BOTHERED AND BEWILDERED:
THE ALLURE OF MISINFORMATION IN A POSTMODERN HEALTHCARE AGE

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Introduction

Much like the star-struck protagonist of Rogers and Hart's ballad, misinformation has the ability of hypnotize its audience. Health misinformation has reverberated through a frenzy of national political discourse, particularly feeding into the myriad of health policy debates happening in and outside of the political spectrum. Affected issues range from attempts to overhaul Obamacare, to the creation of new health insurance markets but also, and more importantly, the influence of smaller-scale, personal decisions surrounding an individual's own health (Dunn, Leask, Zhou, Mandl, & Coiera, 2015; Moorhead et al., 2013). Misinformation within the public health industry is so pervasive that it still continues to be endorsed, either accidentally or purposefully, by public figures from all parties and platforms (Amith & Tao, 2018). Given the increasing production of health misinformation across social media, especially stories with the clear intent to influence, discredit or subvert scientific norms, and the viral speed at which this type of information disseminates itself, many people believe that health misinformation will be the next, big public health crisis (Caulfield et al., 2018; Larson, 2018; Vogel, 2017).

Health economists argue that the rise of misinformation and its acceptance by individuals can be seen as an extension of the lopsided healthcare relationship (ex. the patient-physician relationship or patient-health system relationship) (Bloom, Standing, & Lloyd, 2008). Inherent in this relationship is the problem of 'information asymmetry', where one party (the patient) requires the expertise of a second party (the physician) in

order to make a decision. This asymmetry gives greater power to the second party with the ability to influence not only an individual, but when multiplied, larger market forces for the health industry (Bloom et al., 2008). Due to this power imbalance, in the age of the internet, patients often try to seek what knowledge they can on their own in order to decrease the reliance on another person's expertise and opinion. The current technology systems we rely on to search for new information are not perfect. Through this window misinformation enters.

Conceptually, health misinformation is complicated. It can be a complete and proven falsehood that due to the story's stickiness, stays within the current narrative and persists (Kata, 2010; Tan, Lee, & Chae, 2015). However, more often misinformation is a distortion, embellishment or a realistic sounding theory without scientific support, which people individually pass forward either via social media methods, in public settings or by word-of-mouth (Kata, 2010; Tan et al., 2015). Web browsers are combating the prevalence of misinformation in search results by linking resulting sites with established scientific publications or institutions (Vraga & Bode, 2017). This effort is still on-going, but most misinformation spreads due to the nature of social media platforms and the churn of algorithmic culture (Caulfield et al., 2018; Tan et al., 2015; Vogel, 2017). An ontology to classify and categorize types of misinformation on the web is currently used to help pinpoint where strategic efforts might be the most effective (Amith & Tao, 2018). Semantic webs and ontologies are commonly used in the biomedical sciences, so this approach to understanding health misinformation follows a similar pattern for public health researchers and evaluators.

Misinformation is often used to undermine trust in an institution or erode support for a particular viewpoint (Collier, 2018; Larson, 2018). The origins of health misinformation can be found in a now debunked study published in 1998 linking the prevalence of autism to the childhood MMR (measles-mumps-rubella) vaccine (Kata, 2010; Larson, 2018). While the scientific community acknowledges that Wakefield's flawed study should have been retracted immediately after its publication, it was not refuted until 20 years later. Its publication occurred during the early days of the web and this study lay buried and dormant until decades later when the anti-vaccination movement uncovered it, and propelled it to the forefront of national conversations. Despite major campaigns to re-educate the public about vaccines and adamantly refute Wakefield's findings, as well as demonstrate the faults of the study, this is a story that many people continue to believe and the effect on vaccine education is still felt today in clinical healthcare (Berezin & Eads, 2016; Marshall, 2015; Shelby & Ernst, 2013).

While some health misinformation can be attributed to the propagation of 'bad science', studies that do not adhere to accepted scientific research norms or are not fully conceived to remove bias, making their findings contested, still make their way into the purview of public conversations (Marshall, 2015; Vogel, 2017). The unregulated nature of the internet provides an easy platform for these studies to communicate en masse (Vraga & Bode, 2018). The rise of misinformation as a public concern can also be equally attributed to the social shift in broader cultural expectations, and the changing dynamics of autonomous health decisions (Berezin & Eads, 2016). With the policy push towards informed consent in healthcare and a greater emphasis on independent health decisions, patients are less likely to accept a clinician's recommendation as wise counsel

without argument (Amith & Tao, 2018; Vraga & Bode, 2018). While the power of medical decisions should without a doubt rest on the individual, not the system and not the government, this dynamic shift has allowed many to dismiss expert and verified health recommendations as false and untrustworthy (Collier, 2018; Larson, 2018; Vraga & Bode, 2018). With the age of informed consent and HIPAA privacy protection, we have now also ushered in an information age that builds on the fears of those who hold the decision power. The larger emphasis on autonomy as a societal value, the presence of fearmongering and the lack of a balanced counterpoint, as well as missing informational oversight or gatekeeping, has created a perfect storm assuring that people react in emotional and non-informative ways (Collier, 2018).

Various avenues have been used to combat the prevalence of health misinformation and its impact on the public. As mentioned earlier, search engines such as Google have started to link search results to accredited and trustworthy publications and institutions, demonstrating a strength in accepted “networked” research to help individuals access correct information (Vraga & Bode, 2017, 2018). Health experts have also been used to counteract false health claims (Vraga & Bode, 2017). However, given the nature of social media and its business drivers, as well as the presence of famous social influencers who push particular viewpoints (scientifically accepted or not) (Dunn et al., 2015), these efforts by public health experts are both dwarfed by the sheer volume of data that misinformation can generate in a short amount of time, and are outmatched in the power they have to “out-influence” a professional influencer (Vraga & Bode, 2018). This current picture of social media’s inner workings is what skyrockets health misinformation, putting the public health industry on defense.

Sadly, the underlying truth is that with the combination of the dark side of the internet and current information seeking behavior, exposure to the correct content is not enough to dampen the allure of misinformation (Vraga & Bode, 2018). Individuals seek out information which already corresponds to their own world view (Caulfield et al., 2018; Tan et al., 2015; Vogel, 2017). This is further reinforced by the algorithmic nature of search engines which feed results profiled to match a person's previous preferences (Russell-Rose & Chamberlain, 2017). To change a person's way of thinking, there needs to be a catalyst for a personal paradigm shift which changes their world view (Collier, 2018). This is not an easy feat. The internet is so vast that any person can find something which sounds authentic and speaks to their own world view. To counteract misinformation, people need to be not only engaged, therefore actively receiving information, but also develop skills that ask them to critically analyze the information they are presented with. What story is being told and is this trustworthy and/or from a trustworthy source (Shelby & Ernst, 2013)? Exposure to correct content on its own is unlikely to leverage this kind of behavior shift. The strategy for inspiring this kind of change needs to be multifaceted and multidirectional. The problem of misinformation is complex, making the solution complicated, and this conundrum may prove to be one of public health's most difficult mountains to surmount.

Vaccines and Misinformation

Historically in the US, vaccines have always been contested in some way. Despite this, childhood vaccination policy is considered one of the best examples of public health success (Orenstein, Douglas, Rodewald, & Hinman, 2005). Since the inception of the

program, an anti-vaccination movement has been in existence, mostly to counter-balance government influence on individual decisions (Berezin & Eads, 2016), and in a country like the US, where freedom of choice and liberty are valued identifiers of our culture, vaccine policy has therefore always had some form of an opt-out program. While the strength of the anti-vaccine movement ebbs and flows throughout the decades, recently, the debate has revived with celebrity endorsement and coincidentally, as a target for bot interference via social media (Broniatowski et al., 2018). Online bots have been a familiar subject in the public discourse recently given their role in the 2016 election and other hot-button topics. However, in the instance of vaccines, bots were used to both spread vaccine misinformation at a rate faster than human interaction, and to also increase the level of the entire conversation (i.e. spreading not only misinformation but also correct information regarding vaccines), thereby normalizing the anti-vaccine discussion (Broniatowski et al., 2018). This normalization makes misinformation seem more legitimate and trustworthy to those seeking answers (Smith, 2017). The impact of this influence, the loss of faith in vaccine effectiveness due to misinformed people, can be seen in the declining numbers of vaccinated children (Berezin & Eads, 2016; Gyenes & Xiao Mina, 2018). By choosing not to vaccinate, individuals reduce the ability for a population to reach herd immunity – a necessity for diseases to be eradicated (Gyenes & Xiao Mina, 2018). Researchers have already noted a resurgence of childhood diseases, such as measles and pertussis, that had mostly been eradicated in the US (Berezin & Eads, 2016; Fisher, 2015; Phadke, Bednarczyk, Salmon, Omer, & Health, 2016). This is only one current example demonstrating that misinformation, and the

decisions made from incorrect information, can affect an entire population, not only the individual.

The HPV Debate

The HPV (Human papillomavirus) vaccine is historically one of the most controversial vaccines provided in the US. Although heatedly debated, it has been thoroughly researched with evidence to support its effectiveness and safety (Dunn et al., 2017; Hawkes, 2018; Markowitz, Gee, Chesson, & Stokley, 2018). The HPV virus causes four different types of cancer, the most notable being cervical cancer. The vaccine has a 100% coverage rate once completed (there are 3 shots in the vaccine series total) (Markowitz et al., 2018). There are many reasons which make debate around this particular vaccine fiery. The mode of transmission for infection is via sexual activity and coupled with the ideal target age of 10-12 years, conversations surrounding the HPV vaccine coexist in a space which also contemplates the age of sexual awakening (Intlekofer, Cunningham, & Caplan, 2012; White, 2014). It further stirs up questions regarding how parents prepare or don't prepare their children for sex, and understanding consensual sex (Tyring, 2010). Compounding these complicated social issues attached to the HPV discussion, is the history of the vaccine and how it was approved for market. It was originally only FDA approved for girls and when it was eventually approved for all genders, there was very little media attention given to the new message (Markowitz et al., 2018). In fact, not even all healthcare clinicians were informed of the new vaccine recommendation. Additionally, the types of cancer which develop from HPV mostly affect women and overall, HPV and its message is seen as a female problem. It should be

noted that cases of cancer due to HPV exposure do develop in boys, which is why there is a recommendation to vaccinate everyone. Moreover, power inequality is also linked to the HPV gender debate, similarly to the debate around birth control and abortion services (Branković, Verdonk, & Klinge, 2013). Since the legislature, particularly in North Carolina, is comprised of mostly men, determining the value of this vaccine, which caters to an issue labeled a women's problem, has historically been ignored. Therefore the fallout from the media circus, misinformation and public opinions has never truly been directly addressed (Colgrove et al., 2010).

Generally speaking, vaccine policy is determined at the state level (not federal), so states in the US all have different standards for vaccination. Childhood vaccines, such as the Tdap and MMR, are widely required for admission into the US public school system. Vaccines which target adolescents, are generally given more leeway and have more opt-out provisions. This is usually due to the nature of the vaccine and the lobbying power of parents (Berezin & Eads, 2016). While adolescents (16+) can consent to some health decisions without notification of their parent or guardian, most are unaware of this power and chose to concede to the wishes of the adult authority. HPV misinformation has targeted both teens specifically, preying on an age group that is already stressed on multiple levels, and the parents of teens who ultimately make the individual decision to vaccinate their child or not (White, 2014). Fueled by concerns and worries about HPV and its questions of sexual encounters, adults are often as susceptible as teenagers to misinformation, propaganda and misguidance (Tyring, 2010). The ambiguous nature of health policy feeds into the power of misinformation on its target audiences (Dunn et al., 2015, 2017; Phadke et al., 2016). Furthermore, policy inaction and lack of clarity

underpin the HPV debate, and the internal struggles of those parties involved make the entire situation incredibly vulnerable to influence and the dark side of social media.

Research Question

Within the HPV debate, how does the ambiguity of North Carolina vaccine policy create opportunities for misinformation to flourish

Literature Review

The advent of social media sparked new ways for people to send and receive information, to connect and to be informed. The exponential growth of narratives allowed users to view multiple messages at a time, creating a way for them to decide which message spoke most to themselves. Social media by definition functions as a communication outlet, but ‘social networking’ is described as the dissemination of information, sometimes direct and sometimes two-way, to several other parties linked together by connections or networks (Moorhead et al., 2013). From these connections, communities develop (Caulfield et al., 2018; Moorhead et al., 2013). Many studies have been conducted to evaluate the impact of social media on health communication. Social media is ubiquitous nowadays with patients, experts, physicians and institutions all participating, bringing new dimensions and obstacles to how public health can educate and collaborate with other parties in order to achieve their ultimate goal of improving health outcomes for the population.

As a tool, social media offers public health avenues for different types of information to reach different groups. The health information provided generally to the

public ranges from answers to medical questions, information about seasonal viruses and symptoms, as well as health warnings (Denecke & Nejd, 2009; Kim & Kwon, 2010; Kontos, Emmons, Puleo, & Viswanath, 2010). An advantage to social media is that information can be provided in forms alternative to text, such as video, reaching a broader range of audiences (Adams, 2010b; Moorhead et al., 2013). YouTube in particular has demonstrated itself as a helpful tool for potential patients to learn about medications and diagnoses in lieu of reading a pamphlet or article containing the same information (W.-Y. S. Chou, Hunt, Folkers, & Augustson, 2011). Blogs are also an important opportunity for experts and patients to share knowledge, whether that is personal experience or professional input. Social media has also seen the rise of online communities, commonly formed by people with common diagnoses or experiences (Colineau & Paris, 2010; Farmer, Bruckner Holt, Cook, & Hearing, 2009). These communities develop as strong support systems for those suffering from debilitating illness but also as an important means to engage with other's seeking similar information. While the social aspect of these groups is important to healthy outlooks and patient engagement, it should also be noted that these are typically private spaces not monitored by a physician or health expert, so the health information divulged is similarly not regulated. Social media is also used to rate or monitor clinicians and health institutions (Lagu, Hannon, Rothberg, & Lindenauer, 2010), and to promote larger community or population efforts. While these efforts help the health community stay visible to the public and potential patients, the information generated from mixed reviews can also create a hesitancy on the part of new patients as they attempt to find perfect options. In more experimental settings, social media is also being researched as an option for direct

patient consultation (Hawn, 2009). While there are many regulatory questions that need to be addressed, the convenience of social media platforms providing this type of service appeals to many.

Health communication provided via social media has proven to be beneficial to several different healthcare stakeholders. Patients particularly like the fact that social media can tailor information directly to them, thus making it more personal (Moorhead et al., 2013). The volume of health information has also increased, making resources more available and accessible to many people (Adams, 2010b). Using social media platforms to disseminate health communications has shown engagement with those who might not have been able to access the same information via traditional methods, namely younger generations and those of lower socioeconomic status (W. S. Chou, Hunt, Beckjord, Moser, & Hesse, 2009; Kontos et al., 2010; Lariscy, Reber, & Paek, 2010). Of course, a patient would still need access to social media in order to receive this information, so an access barrier is still present and will exclude those communities with poor technological infrastructure. As detailed before, the peer group experience, providing social and emotional support has shown a positive effect on patients suffering from illnesses. Behavior change is more likely to be influenced by peers than health experts, so these online communities are becoming increasingly important to living healthy lifestyles (Colineau & Paris, 2010). Furthermore, the omnipresence of social media also allows for better surveillance and monitoring of public health initiatives and disease incidence (Chew & Eysenbach, 2009). A major portion of public health efforts detail monitoring and containing outbreaks when they occur. Social media has not only allowed for a decrease in the effort required for mass surveillance (and cost) but also quicker response

times, since data can be collected and analyzed closer to real time. This surveillance capability has also allowed researchers to study aggregated public reactions to health initiatives (Corley, Cook, Mikler, & Singh, 2010; Salathé & Khandelwal, 2011). This information has the potential to make outreach more effective and help update current health policy to be more successful in this space (Moorhead et al., 2013).

Given the open nature of the internet, and by extent social media, research has also uncovered limitations to health communication and information in this space. The main concerns surround the quality of the information (Adams, 2010a; Nordqvist, Hanberger, Timpka, & Nordfeldt, 2009) and a lack of reliability (Farmer et al., 2009). Authors, especially in non-academic spaces, are often not identifiable or anonymous, blurring truth and falsehoods. The production of health information online also places the burden of discernment on the user or audience member to determine whether the information provided is trustworthy (Moorhead et al., 2013). There are several problems with this conceit, namely that individuals generally search for health information to become more informed and don't possess a relative starting point to determine authenticity or trustworthiness (Caulfield et al., 2018). Furthermore, information via social media is readily available and in large quantities, increasing the strain of information overload on seekers (Adams, 2010b). Studies have also highlighted concerns over the privacy, security and confidentiality of patients when allowing access to their data (sometimes necessary to join an online community) (Moen, Smørdal, & Sem, 2009; Nordqvist et al., 2009). Of course, a major limitation of information in this space is the idea that all information is equally presented in search algorithms (Russell-Rose &

Chamberlain, 2017). Health misinformation particularly takes advantage of this aspect of information retrieval, helping to propel its narrative forward.

Studies in rumor theory have investigated the ability of health misinformation to propagate, separate from research into the impact of social media on an information seeking public (Tan et al., 2015). The proliferation and spread of rumor expose a social construct to feel personally included in the elite (the group which the rumor is not about). There are individual level influences and community level factors involved in the propagation of rumors, such as socioeconomic position, resources that facilitate discussion or the lack thereof, and the nature of topics which discourage open sharing (Southwell & Thorson, 2015). Rumor transmission can be motivated by multiple factors including anxiety and uncertainty, as well as a misaligned feeling of altruism (DiFonzo, 2013; Ecker, Lewandowsky, Fenton, & Martin, 2014). The believability of the information is also reported as an integral part of rumor creation and longevity, showing that believability heightens a physiological response with the exposure to rumor and stories. From this response, an individual is more willing to share this information with others (Ecker et al., 2014; Webb & Jirotko, 2017).

Rumors and health misinformation are often characterized by viral transmission since the spread of rumor within a community is similar to that of a viral infection. Within health outbreaks, social media based rumors surrounding the Ebola crisis were found to have spread faster than authentic, informative information, forcing health responders to adapt communication strategies to both inform about the present situation and combat viral misinformation at the same time (Allgaier & Svalastog, 2015; Gyenes & Xiao Mina, 2018). The fallout from the marriage of rumor propagation, a human

behavior, and technology enabled social media, is the creation of grander, easily accessible platforms for misinformation to reside in, raising the level of discourse around health misinformation and sensitizing younger populations to the plethora of misinformation available (Broniatowski et al., 2018). In effect, this volume creates a virtual wall of white noise that many information seekers tune out unless a message speaks directly to them on an individual level. Narrative studies also show the prevalence of confirmation bias and information avoidance on the part of the user (Caulfield et al., 2018). This further embeds already held personal beliefs about a given topic, diminishing the potential success of informative and educational endeavors (Caulfield et al., 2018). A recent study focusing on Twitter interactions over a ten year period demonstrated a clear association of false information with faster, farther dissemination than compared to that of truthful resources (Vosoughi, Roy, & Aral, 2018).

Attempts to correct misinformation have offered few strategies to combat the speed at which this information activates users and is passed on. A few recent studies have shown progress in successfully reducing misperceptions of health information by employing health experts with social media savvy to re-educate their followers (Vraga & Bode, 2017), thereby indirectly influencing a larger network. Having an agent stand in as the face of an organization's stance was more likely to have more of an impact on the public than media statements issued from an institution directly, despite possession of a strong and storied reputation (Larson, 2018). This shows a tendency for the public to believe people over organizations. Attempts have been made to correct misinformation with a variety of algorithms, but most researchers posit that the mechanism to best correct misinformation should come from social sources (Vraga & Bode, 2018). A similar effort

to help develop defense strategies has also emerged from research focusing on the semantic ontology of health misinformation, both its origination and how it disseminates (Amith & Tao, 2018). Ideally, this will afford public health communication teams with the knowledge to inform better, more targeted strategies. In many ways, correcting misinformation is like chess. The direction of misinformation can be unpredictable, but the more understanding a team has about the problem, the player and the motivations behind the story, the better the plan to establish a truthful narrative and subvert health misinformation's goal of disruption.

Despite the HPV vaccine's headline grabbing attention in the media and public acknowledgments that misinformation surrounding this particular vaccine abound all over the internet, not many research studies have looked at the impact of social media on this specific controversy. An observational study has demonstrated a link between negative social media messaging and subsequent reactionary postings (Dunn et al., 2015). Negative HPV messages invariably plant the seeds for more negative rhetoric and opinions to emerge about the vaccine. Negativity begets negativity in a cycle that has yet to stop. This study particularly analyzed the HPV conversation via the Twitter social structure, but its findings are likely transferrable across other social media platforms (Dunn et al., 2015). Similarly, other studies have mapped the exposure of HPV misinformation with HPV vaccine coverage across the US, again showing a direct influence on individual health decisions by information found on social media (Dunn et al., 2017). When controlling for socioeconomic factors, the level of HPV rhetoric and vaccine misinformation from users of Twitter remained higher in states with lower vaccine coverage. The higher exposure to conspiracies and false information in these

states undermined public health efforts working towards HPV vaccine acceptance, leaving researchers to support the statement that negative representations of vaccines influence their acceptance into standard clinical healthcare (Dunn et al., 2017). Lastly, longitudinal studies have also tracked the impact of misinformation as political statements made in public spaces, and the use of the media as a propaganda machine (Mahoney, Tang, Ji, & Ulrich-Schad, 2015). A false statement made with confidence in the political arena or within the context of debate, is rarely retracted nowadays. Instead, at this time in history, political opponents possess media machines that continue to systematically argue the point, whether fact or false. This new instinct to fight rather than concede and apologize, allows the public to see misinformation as an issue worthy of debate (Mahoney et al., 2015). The media, its tone and its dissemination of news, still hasn't fully admitted its role in propelling health misinformation into public discourse, but evidence is gaining steam to show how the media is another important facet feeding into the proliferation of health misinformation and its aftereffects.

While health policy changes have been called upon by a multitude of researchers to help contain and combat the effects of health misinformation on individuals, the introduction of new health policy and analyses reviewing the fallout of incorrect health information, its means to enter into the health decision-making process, and reasons behind its acceptance and success, are nonexistent. Health misinformation traditionally has been the sole responsibility of public health offices ill-equipped to deal with the many challenges arising from the persistence of false information in public conversation, let alone develop detailed strategies to eradicate it. This study seeks to compare the conversation found in the public discourse surrounding HPV and its vaccine, with the

conversation presented by North Carolina state vaccination policy. While this proposal does build on previous social media, health and communication focused research, it also introduces a sorely needed policy analysis component. The underlying supposition being that health misinformation around HPV continues to persist even in the presence of experts who debunk false information and an educated public with the means to find trustworthy and correct information, because the ambiguity of North Carolina's state vaccination policy provides a space for misinformation to live in, easily adapt and therefore continue to thrive in public discourse.

Methods

Given the qualitative nature of health misinformation and health policy, content analysis was a logical methodology for this study. Content analysis allowed for the consolidation and categorization of information, creating in essence a snapshot of the two conversations (Lombard, Snyder-Duch, & Campanella Bracken, 2002). To analyze these stories in the abstract, an inductive approach allowed for emerging themes from both perspectives to create an overall depiction of the larger conversation surrounding HPV in North Carolina. However, content analysis in its purest form served as an incomplete research method, so this study was also underpinned with elements from discourse analysis. Both misinformation lifecycles and state policy fall into public discourse, and given the importance of context and intention to these messages, as well as tone, phrasing, word choices, etc., the addition of discourse analysis to this methodology allowed for the discussion of key elements outside of the strict parameters of content that inform the conversations. This mixed technique allowed for a more comprehensive analysis of HPV misinformation, policy and impact.

Content analysis has long been a favorite research method for analyzing mass communications, especially with the advent of the internet and social media (Chew & Eysenbach, 2009; Denecke & Nejd, 2009; Dunn et al., 2017; Kata, 2010; Lombard et al., 2002; McMillan, 2000; Weare & Lin, 2000). It is a method ideally suited to allow for

similarities to surface and easily grouped together (categorization), and differences to become visible. Content analysis is a systematic process, and is able to accept material in different formats, structured and unstructured (McMillan, 2000). As a methodology, it allows for the emerging nature of themes to determine the overall breadth and scope of the discussion and interpretation of findings. As an advantage, content analysis allows for an inductive process and is therefore “unobtrusive” (McMillan, 2000). Yet, this process is not an all-encompassing nor a perfect method of research study. It relies on the ability of individual investigators to consistently code both the information being studied and between themselves (Lombard et al., 2002). While coding can be completed via computer or by hand, ultimately this aspect introduces a reliance on humans and the possibility of human error or skew as coders will all have their own individual perceptions. We acknowledge that these variations can be minimized but never fully removed from a content analysis study.

This study focused on gathering information surrounding the HPV debate in North Carolina. Collected documents include articles, reports, legislative announcements and policy publications. These documents are backed by organizations or institutions and were gathered from internet accessible sources. This study does not serve to determine individual intentions or opinions related to the HPV conversation; therefore documents were not collected from platforms such as Twitter, Facebook, YouTube or any other individual facing social media. The goal of this study is to research the HPV conversation as it is debated by institutions, either from a government standpoint, media outlet, community or professional organization. The intention of these institutions will be uncovered by their corresponding mission statements, legislative stance or professional

code of ethics and/or conduct. Furthermore, this study analyzed written documents. Formats which include video, press releases, listservs and non-English languages were not included. Documents pertained to the HPV debate in North Carolina specifically, and did not include information originating from other state or international archives. Content analysis of all documents was an iterative process, completed until the point of saturation; where no new themes or categories emerged from the set. This process was not completed with coding software.

Once content analysis had revealed overarching categories, themes and sub-groupings, discourse analysis allowed for the discussion of how these results fit into the context of the HPV debate, whether in the form of rhetoric, propaganda, informed opinion, educational information, etc. HPV is a known controversial topic for many different reasons, all of which vary from person to person, political party to political party, so incorporating discourse analysis grounds these results in the larger public discussion of misinformation and its impact on decision-making, trust, motivation and authority. While this study hypothesizes that HPV misinformation thrives because health policy doesn't provide enough guidance for information seekers to feel secure (i.e. the ambiguity of health policy allows misinformation to fill knowledge gaps with any information, correct or not), the larger public dialog surrounding health misinformation is also an important facet of this conversation and is included in our discussion, partnering with study findings. Ultimately, the goal is to use these results to create a theoretical map of the HPV conversation in North Carolina. Ideally, this serves as a demonstration of how one story, i.e. established health policy in North Carolina, creates opportunities which health misinformation takes advantage of. This cycle of story creation, action and

reaction creates an information cycle which feeds into impressions, motivations and trust in public health initiatives. Success of this study relies on whether a complete rendering of the HPV conversation can be depicted and if new insights can be brought to the forefront of this highly contested issue. Understanding how this type of story cycle develops and establishes itself can not only help new public health initiatives succeed but also provide new ideas for how this industry can begin to earn public trust back.

Additionally, discourse analysis is also an intuitive fit since, at its core, this study is a comparison of two different stories. Discourse analysis allowed for the discussion of different types of conversation. The first discourse perspective uses language as “message-oriented” and aligns well with the messages found in misinformation. There is a personal belief and credibility to the message that makes it acceptable to the listener/audience, regardless of truth (Budd, 2006). The second discourse perspective is discourse as a social act. It is formal communication that calls on the power of institutions, norms, customs and traditions to be effective (Budd, 2006), similarly to how state governments enact policy. Content analysis and discourse analysis have similar research processes (Budd, 2006) and this two-pronged research method served as a unique but logical way to analyze the two main stories of the HPV debate.

While this study attempted to remove as much bias as possible, an expectation of complete removal would be unrealistic. Healthcare and public health are the researchers’ career industries and consequently, we possess a deep understanding of the difficulties health institutions face in light of the prevalence of misinformation and the effort exerted to argue various stances. Bias in information retrieval is also likely to be present, although every attempt to minimize it was taken. Information searches and document

collection were performed on a number of public computers in order to minimize personal search biases. Since information was gathered via the internet, it is acknowledged that search engines are algorithmically designed to provide results in line with an individual's personal profile. In the age of the internet, we recognize that search profiles likely reflect our support for public health initiatives, academic research, liberal political stances, as well as our work with health engagement and clinically focused healthcare. The use of public computers for document collection was necessary to locate information outside of these established filter bubbles. An inclusive set of documents showcasing different ideas, opinions and dynamics of the HPV debate was gathered via purposive sampling, in order to capture all key viewpoints expressed in the HPV discussion.

Results

The Public Conversation

In order to measure the extent of the public conversation surrounding HPV, its vaccine and its impact, forty-five (n=45) documents were located from a variety of organizations and internet sources. In total, these documents represent a diverse set of messages, many of which contradict one another. All focus on a myriad of different facets surrounding the HPV debate ranging from strategies to help promote the vaccine, to conspiracy and anti-government sentiments, to efficacy and legislative concerns. Documents consist of news reports (local and national), statements from professional societies, academic research institutions, established advocacy groups and online articles written for magazines or organizational blogs. By far, the most diverse category in terms of topic, tone and mission were statements pulled from advocacy groups. Although this set makes up only a small portion of total documents (19%), the articles cover the full spectrum of HPV viewpoints, from fervent support to absolute disapproval. This topic spread is something not found in any other sub-grouping, as other documents grouped together by source tend to have more consistency in terms of similar tone and/or argument.

A Different Vaccine

In a majority documents (54%), HPV is portrayed as a “different vaccine.” Context surrounding this distinction pulls from both its turbulent marketing and implementation history as well as larger discussions of its impact on current vaccine legislation debates and overall cultural acceptance. In almost every case, HPV is set up as being set apart from a norm. For example, the HPV vaccine is often compared to the other vaccines given to the same age group, meningococcal and Tdap. Many reports note that acceptance of the HPV vaccine is more likely to occur when it is bundled with these other “normally accepted” vaccines and this is a strategy professional societies often advise their constituents to employ. However, despite this, HPV is often discussed as “optional” or “other,” lending credence to the impression that it is different in some way, and therefore less valuable.

HPV is also set apart by its distinction of being a preventative tool for a sexually transmitted disease (STD). This is the only vaccine developed to defend against any kind of STD, which makes it unique. However, according to most documents, this particular uniqueness or characteristic is the major factor feeding into vaccine hesitancy. While many documents support a messaging shift from conversations about sex to those about cancer prevention, most of the messages analyzed here often call out HPV for its difference as relating to the nature of sex, with several documents remarking on the belief that this discussion “green lights sex for teens.”

Findings also describe how HPV, in particular, has the ability to immediately splinter public reaction via distinct cultural divides upon mention in any discussion. A public reaction in this sense is the first of its kind. Many articles detail HPV as becoming

a “lightning rod for emotion,” often describing conversations around HPV as politically or culturally motivated, not scientifically. Documents also note HPV’s ability to bring minority health and gender issues to the forefront of discussion, topics that can intrinsically lead to heated discourse on their own. Nevertheless, this intense public reaction is, so far, highly attached to the HPV vaccine and not any other vaccination or public health initiative, making this a lasting and persistent controversy, even when analyzed a decade later.

Trust

Trust is a frequent concept referenced throughout most documents (57%). Discussions around trust take on different forms. Trust, from a parental perspective, manifests as questions regarding the actual safety, side effects and efficacy of the vaccine. Many documents report that parents still don’t believe the HPV vaccine as anything more than a placebo. Documents focusing on parents also acknowledge trust issues between parent and child. This is often showcased as a reported belief that HPV vaccination is the same as granting permission for sexual activity. They further describe how parents lack the realization that their children are actually at risk for an HPV infection. This is despite the evidence of an increased incidence and prevalence of infections in the US (CDC, 2014), and details an inherent distrust for collective, statistical information which contradicts their own personal understanding of the situation or world view. Moreover, while health providers are now likely to support the HPV vaccination on its scientific merits, parents are still unlikely to trust this same information from their child’s providers as well.

In a larger context, trust issues manifest when discussing government policies or lack thereof, as well as lobbyist firms and the power of drug companies, namely Merck, the creator of the HPV vaccine. Many documents uncover a growing distrust of government institutions and the processes for vaccine approval. Several reference that Merck was granted an accelerated approval process for the HPV vaccine, underscoring a lack of trust in the government to properly verify efficacy and safety elements of new vaccines. A small number of documents go so far as to describe a more conspiratorial government cover up and drug company ploy. The lack of trust in government and safety processes, and the belief that a system of checks and balances regarding drug development and drug profitability is not in existence, leaves many articles to speculate that while there may be a decade worth of positive research supporting HPV, until this narrative changes HPV may always be considered a failure in the public eye.

Vaccine Legislation

While not all documents cover the state-focused legislative debate surrounding new vaccine law, a significant number highlighted this as a major topic in the HPV discussion (42%). HPV, with its cancer prevention track record, has spurred proposed changes to current vaccine law, not only in North Carolina but nationwide. Documents detailing HPV legislation are particularly targeted towards parents, their views about the vaccine and what measures they would willingly comply with. An interesting discernment regarding this particular facet of the HPV discussion (possible vaccine legislation) is that most articles describe high parental support for HPV legislation if an opt-out clause is also introduced. However, articles speaking to not only parents but

health professionals, academics, policy analysts, etc. argue that while parental support is vital for a new piece of legislation to pass, an opt-out provision will invariably make any new law ineffective. This impasse is detailed in every article pulled for review which focus on HPV legislation. No other commentary is offered. Many documents reference the controversy surrounding then Governor Rick Perry's executive order for HPV vaccination in Texas. The resulting public backlash killed this mandate almost immediately and this example often serves as a failed test case. While some documents mention a vaccine mandate as a feasible policy option, all of them discourage it. This stalemate indicates that this issue, particularly in North Carolina, remains murky, mixed and unresolved.

Competing Arguments

Broadening our analysis perspective, most documents position themselves on a particular side of the HPV debate. While a small number (16%) were staunchly neutral, nearly two-thirds argued in support of the HPV vaccine (62%). These 'pro' argument documents saturated every source and were written for all target audiences (parents, health providers, general public, etc.). They touch on the controversial legacy of HPV, the reasons behind vaccine hesitancy and offer strategies to potentially increase acceptance. From a readability stand point, 'pro' arguments are written in a direct manner as to provide facts. These articles particularly rely on scientific results and evidence, often referencing current HPV research to support their statements. Most of the documents analyzed in support of HPV vaccines are written with the supposition that

decision-makers want scientific facts and statistics to help them decide on a course of action.

On the contrary, those documents inhabiting the ‘against’ position take a much different strategy. While there is a smaller portion of these documents within the analysis (22%), it is not so small as to be labeled insignificant. These articles are written less about statistics and more about personal stories involving the HPV vaccine, usually tragedies. Personal narratives offer a different way to engage decision-makers, creating an environment to identify with the ‘against’ position on an individual level. These documents are also likely to employ the use of photographs to engage their audience. An important note, two articles which state ‘against’ positions take this stance due to evidence that the HPV vaccine versions currently available are not as effective in the African American population. They do support the development of a new version of the vaccine for African American patients and HPV vaccination in general.

While looking at these documents through the lens of their pro/against positions emphasizes interesting insights, it also offers a different viewpoint for analyzing potential pitfalls in storytelling. Both ‘pro’ and ‘against’ arguments reference current medical research, both use the phrase “scientific evidence”, and both leave it up to the reader to determine the validity of such scientific studies. While both sides of the argument are attempting to justify their position, analysis from this vantage point shows a classic discussion of public discourse. As the HPV debate has in many ways become a touchstone for culture, high context and low context characteristics of communication can be found throughout the breadth of documents. The ‘pro’ argument calls on discourse as a sense of tradition and public good, stressing social relations. It employs the use of

statistics to infer that the argument is sound and safe, and an individual should be vaccinated since they believe these larger institutions are credible. The ‘against’ argument uses a message-oriented approach to discourse. This information is believable because the author or leader is considered credible. The use of personal narratives and lexical similarity - explicit language meant to speak to its audience, is much more apparent on this side of the argument. Much like the stickiness of misinformation, this type of discourse relies on the emotion that underpins this debate more so than responsibility to the greater good.

The Policy Perspective

To capture the current picture of vaccine law and recommendations in North Carolina, documents were collected from the North Carolina Department of Health and Human Services (NCDHHS), the Centers for Disease Control (utilizing a national database for all current state vaccine requirements) and the North Carolina General Assembly. While there were only eight (n=8) documents recovered for analysis, the total set covers the extent of vaccine law, and the responsibilities and allowable exemptions in North Carolina. Only three documents mention the HPV vaccine specifically as it is officially recommended for adolescents by the state, but it is not on the list of vaccinations required by law.

The documents which refer specifically to the HPV vaccine detail a case of support for vaccination similar to the documents analyzed in the ‘for’ argument. They provide a narrative via statistics, symptoms and cancer prevention. The NCDHHS in particular emphasizes support by providing several different physician endorsements. The

bulk of information provided in these documents detail who should get this vaccine and why. Emphasis is on cancer prevention as a recurring theme throughout these documents, employed mainly as a vector to encapsulate the HPV story for its audience. Also mentioned is vaccine cost and alternative programs for free vaccines, themes not generally found in the analyzed public conversation.

Documents pertaining to general North Carolina vaccine law restate previously mentioned information regarding vaccine requirements prior to entering or continuing with school (grade school and university level). Since HPV is not a required vaccine in North Carolina, much of this law does not apply to this debate. Parents do not have to provide a formal exemption to refuse the HPV vaccine. Still, it is highly recommended, therefore legislation was introduced to include HPV vaccine education by schools, together with educational materials for other required vaccines. This bill was passed to ensure that parents and guardians were educated as to the vaccine's benefits and recommendations, despite its lack of requirement by the state. The distribution method and format of this education is largely at the discretion of the school system. These documents highlight the responsibility of the North Carolina school system to uphold health and safety standards, a point also not mentioned in the public analysis.

Discussion

While it is not in the purview of this study to determine the truthfulness of each document, and therefore whether it is or is not misinformation, it is clear in comparison that the themes found within the public conversation are not the same as those stated in the health policy perspective. These two stories indicate different agendas, needs and wants. For stories that should, theoretically, mirror one another, these are mismatched rather than connected.

The public conversation, as pieced together here, reflects the turbulent history of HPV. It demonstrates many different themes and topics, which when analyzed, often move in disparate and fractured directions. This is similar to the way that stories surrounding HPV, both truthful and untruthful, grew and developed. It is clear that the piecemeal and ill-informed way health information was relayed to the public not only inspired the creation of the messages found here, but also guided them towards the avenues they needed to occupy in order to stay within the public narrative. Since collected documents were released over the course of several years (2011-2019), analysis shows that given the haphazard nature of HPV vaccine promotion, alternative messages were easily able to find information gaps and fill them. Misinformation at its core needs the presence of knowledge or information gaps in order to survive and persist. This can be in the form of a true lack of information or in the uncertainty that leads a person to

believe and trust a source over more reputable information. Analyzing the public conversation alone, shows multiple viewpoints, theories and ideas all vying for attention in the vacuum created by an unsure and ineffective government plan. Given the nature of the information age, relevance ranking algorithms and content curation, it is easy to imagine how an audience could easily be coerced into seeing only a single, narrow slice of the HPV debate. The messy nature of the themes and sometimes irreconcilable views and opinions found within these documents demonstrate one of the greatest opportunities for misinformation to persist.

Collectively, the public story represented in these findings highlights the most important aspects of the HPV conversation as determined by its audience, the health decision-makers. The mismatch between public and policy shows that what the public values in terms of necessary information (i.e. what information they need in order to make the best decision) is not the same as what the legislation deems necessary to write into law. It is possible that the many forms of fear and distrust found within these documents could be assuaged by a better alignment of information needs between public and government policy. The presence of trust/distrust in particular is a major theme detailed throughout the public conversation and it is also a necessary ingredient for the propagation of misinformation. Misinformation is purveyed by sources deemed trustworthy by an individual, making it believable despite the inclusion of fact or not. Trust operates in a space equally occupied by the concept of distrust. Inherent in credible misinformation, is an opportunity to prey upon a distrust of some aspect related to the main topic, in HPV's case it's distrust of government policy, drug companies, vaccine safety measures, teenage sex and healthcare providers. Policy should acknowledge that

lack of public trust hands power directly to misinformation. Government agencies need to rebuild trust with communities and individuals, sealing knowledge gaps misinformation can take advantage of. Given the inescapability of information, this should start with a goal towards information transparency on the legislative side.

Relatedly, fear is closely tied to the concept of distrust. Fear and fearmongering are tools misinformation adopts in the form of rhetoric, scary speech and tone, to influence a person feeling uncertain and/or powerless. With the inclusion of fear tactics, misinformation becomes more powerful in the HPV debate because it can draw on a personal, individual emotion, something a supporting statistic is less likely to accomplish with similar effect. Arguably a more equal understanding, i.e. similar stories, from public and policy would reduce areas targeted by fear and distrust, therefore reducing the areas misinformation can potentially occupy.

Comparatively, the vaccine law/government perspective provides a straightforward, clear cut formula for vaccine compliance. The focus in this story is on giving the public a clearly defined path to follow. The audience is able to understand the exact procedures necessary in order to vaccinate their children per state guidelines, a list of required vaccines to attend school and explicit information about medical or religious exemptions. This is all information health decision-makers want and need to know. While the original supposition of this study was that vagueness and ambiguity plague the policy perspective, in actuality, according to this analysis, what these documents truly suffer from is incompleteness. The information that is available is mostly procedural and educational material, and generally doesn't tap into the big topic concerns contested within the public sphere. To some, this could be interpreted as the government ignoring

these concerns. However, presumably, legislation is written in a high-level, vague format, in order give it flexibility to weather future changes, expectations and cultural shifts. This is a common strategy when developing new laws for endorsement. Nevertheless, in the age of information, providing additional resources to acknowledge valued concerns from the public could also serve as a way to combat misinformation before its inception, answering the information needs before they grow into larger problems.

As previously commented, only a small number of vaccine-related documents were available from government agencies in North Carolina, almost as if the policy story described here is one of “the bare minimum.” Also, these documents rest on a semantic web of sorts, referencing and linking to other government material at a much higher rate than those in the public conversation. While the intention with providing networked material is probably to decrease the duplication of information, the need to continuously click through web pages to find information presents itself as an obstacle for the audience. Frustration at this information setup could lead health decision-makers to look for information in other places, another opportunity for misinformation to enter the narrative. This setup, coupled with the bare-bones information provided to the public, aligns with lasting impressions of government agencies slow to recognize and act against HPV misinformation with relevant and current information strategies. Misinformation can take advantage of systems outdated in terms of meeting the information consumption requirements of its audience and can easily provide platforms for those issues not acknowledged by the legislative perspective. Yet, even if the policy system was optimized to better serve information seekers, since the internet is, more than anything, a data generation machine, the small number of documents pertaining to state vaccine law,

regardless of veracity, can easily be buried by half-truths and other “relevant” findings currently generated at a much more persistent rate. To combat this, government agencies may seek to partner with advocacy groups or other like-minded institutions to increase discourse on their side of the debate. Or they may opt to develop more informational material in-house to address public concerns, therefore increasing the total number of documents relevant to the HPV audience from their perspective.

Worth mentioning, even as the policy story analyzed from these documents reveals a possible incompleteness, all documents directly encourage decision-makers to speak with a person, either healthcare provider or agency representative. This could potentially open dialog to include those issues found in the public conversation. The written documents collected in this study tell only part of the story and many people seek health advice from appropriate in-person sources. We acknowledge that this facet of the HPV debate is not included here. While ambiguity of health law was not, in the end, the correct definition of this policy story, our analysis did uncover a failure to understand what information the public would need to feel safe and accept HPV as a vaccine worthy of their children. This incompleteness or failure gives misinformation the potential to flourish.

The internet, and social media in particular, is changing the nature of health information exchanges (Caulfield et al., 2018). The execution of both these stories (public vs. policy), in terms of audience engagement, can be examined with a sense of déjà vu. Our findings align with previous research investigating how misinformation attracts and engages its readers. ‘Scienceploitation’, a term coined to encompass the combination of hype and rhetoric speech with scientific language, to confer a sense of

legitimacy, is particularly relevant here (Caulfield et al., 2018). Documents supporting HPV vaccination, as well as those against it, employ this tactic to varying degrees. As alluded to earlier, the crux of believable health information still falls on the shoulders of the audience. Employing easy to read writing, scientifically sounding language and a personally directed narrative (i.e. showcasing a personal experience with HPV) is something misinformation does particularly well and in a higher abundance, therefore making it easier as an audience member to listen to their message and believe it. While these types of storytelling elements were also found in documents supporting the HPV vaccine, for the most part, ‘pro’ argument articles rely on statistics and institutional reputation to attract their audience and keep their attention. In terms of engagement, this is unlikely to have as much of an impact as those employing personal experiences. This division between narrative styles may one day become a definitive method for analyzing potential misinformation, but for now, this study’s results serve to add additional support to previous research investigating changing information narratives and the propagation of health-focused misinformation.

Ultimately, this study offers one explanation for the growth and persistence of health misinformation in the public sphere. Using the lens of HPV, its controversial history and larger cultural implications, we were able to determine a mismatch of information needs between the HPV audience and its legislative requirements and recommendations. While in North Carolina, vaccine policy was not found to be as ambiguous as originally hypothesized, findings do suggest an incompleteness in addressing the information needs of the population. The public conversation, as detailed in these results, offers more insight into larger concerns not acknowledged by

government material. Undeniably, these two stories are out of sync and misaligned. This reality gives misinformation more power and more opportunities. The hope is that this research, along with similar studies in health misinformation and information seeking, will help public health recognize the need for more answers and develop better tools and outlets for those searching for information. With a stronger, more fleshed out narrative, more dialog, and fewer questions, the problems stemming from health misinformation can ideally be minimized. Strategically, if misinformation is successful due to its engagement tactics, then public health should consider adopting those same tactics and take back the HPV narrative. While fearmongering will undoubtedly be a tactic the public health industry avoids, the true goal would be to develop communication and information approaches with the same emotional impact as those found in misinformation. The ability to ground a message in emotion is the strongest tool in terms of audience engagement. If public health could re-work their messages to have the same emotional engagement, this would level the field in terms of the power that misinformation holds. Admittedly, this is easier said than done. Given the resilience of the controversy, it is entirely possible that HPV is, politically, a tainted subject and support for this particular debate may wane sooner rather than later. However, as the push towards Healthy People 2020 comes to a close, and a reality where the HPV vaccination rate is unlikely to reach its target goal of 80% sets in (The Office of Disease Prevention and Health Promotion, 2019), the question remains, can public health come together as an industry and evolve their communication strategy so that HPV becomes the last misinformation catastrophe? The hope is yes.

Limitations and Future Work

While the findings investigated in this study offer interesting insights into the reality of health misinformation, limitations are present. The beginning of the HPV debate can be traced back to the release of the original HPV vaccine in 2008 and documents from those initial years are included in this study. However, given the ephemeral nature of the internet, it is likely that not all HPV documents were archived or accessible, and therefore not located in our information searches. Particularly, we suspect that there was a greater number of documents with alternative messages. The misinformation explosion surrounding HPV was one that society had not witnessed before in modern history. Social media, Facebook especially, have since enacted strong measures to prevent new misinformation related to HPV from being published to the internet. Search engines have also systematically removed previously archived inaccurate documents. While the HPV debate is still going strong with respect to legislative changes, the fervor surrounding the proliferation of HPV misinformation has died down. While still ongoing, many feel like this is a crisis already dealt with. Since this analysis occurs years after the introduction of the HPV vaccine and at some distance away of the information storm it once was, it is likely that the availability of documents recovered for analysis reflect these changes due to the passing of time.

Additionally, a landmark HPV report by the University of North Carolina was released at the start of our data collection period. This report detailed the state of HPV vaccinations in North Carolina and while on the surface it seems like it would be a great addition to this study, the nature of the report focused on an aspect of HPV that was not under analysis. It was not included. However, the magnitude of the report and the

multitude of academic responses to it, along with the coincidental timing of the release, flooded search results during the collection phase. This likely influenced the total number of documents collected in this study.

Moreover, we did not analyze other forms of health communication such as podcasts, blogs or video series. While this study's criteria excluded anything created by an individual, many health organizations and institutions offer information via other communication formats. Lecture series and podcasts are particularly engaging with health decision-makers. Future directions of this work could focus on health misinformation within these other avenues of communication, engagement rates with different media formats and if the presence of misinformation is more, less or the same as that found in written documents. As communication tools continue to evolve, other formats for information seeking will also likely become popular in public consumption.

Furthermore, it should also be acknowledged that the discussion arising from these results is one interpretation. Since this is qualitative research underpinned with contextual historical clues and social meanings particular to this time in history, analysis of these results is performed within the established cultural norms of the present. Future cultural shifts, as well as new and different research perspectives, could change the interpretation, if this study were to be repeated in the future. In the end, this study introduces a path towards combining health misinformation and policy research as an analysis of comparative but related stories. More importantly, this is a first step to include policy analysis into the research conversation surrounding communication, information seeking behavior, social media platforms and the changing nature of enabling technology and information availability

Conclusion

Health misinformation continues to challenge public health. It undermines trust in our institutions and the belief that medicine is meant to heal, not harm. It also creates discussion in the sense that it can force people to confront their own echo chambers and fears, and identify their most important values. As public health communication evolves to defend against health misinformation, it should also evaluate of how well it serves its audience and health decision-makers. While in time, the damage of health misinformation and the influence that it has over people may be neutralized, the hope now is that the lessons gained from the HPV controversy, and its subsequent misinformation fallout, will inform better health information practices and inspire a stronger dialog between policy makers and the public.

Bibliography

- Adams, S. A. (2010a). Blog-based applications and health information: Two case studies that illustrate important questions for Consumer Health Informatics (CHI) research. *International Journal of Medical Informatics*, 79(6), e89–e96.
<https://doi.org/10.1016/j.ijmedinf.2008.06.009>
- Adams, S. A. (2010b). Revisiting the online health information reliability debate in the wake of “ web 2.0”: An inter-disciplinary literature and website review. *International Journal of Medical Informatics*, 79(6), 391–400.
<https://doi.org/10.1016/j.ijmedinf.2010.01.006>
- Allgaier, J., & Svalastog, A. L. (2015). The communication aspects of the Ebola virus disease outbreak in Western Africa – do we need to counter one, two, or many epidemics? *Croatian Medical Journal*, 56(5), 496–499.
<https://doi.org/10.3325/cmj.2015.56.496>
- Amith, M., & Tao, C. (2018). Representing vaccine misinformation using ontologies. *Journal of Biomedical Semantics*, 9(1), 1–13. <https://doi.org/10.1186/s13326-018-0190-0>
- Berezin, M., & Eads, A. (2016). Risk is for the rich? Childhood vaccination resistance and a Culture of Health. *Social Science and Medicine*, 165, 233–245.
<https://doi.org/10.1016/j.socscimed.2016.07.009>
- Bloom, G., Standing, H., & Lloyd, R. (2008). Markets, information asymmetry and

- health care: Towards new social contracts. *Social Science and Medicine*, 66(10), 2076–2087. <https://doi.org/10.1016/j.socscimed.2008.01.034>
- Branković, I., Verdonk, P., & Klinge, I. (2013). Applying a gender lens on human papillomavirus infection: Cervical cancer screening, HPV DNA testing, and HPV vaccination. *International Journal for Equity in Health*, 12(1), 1. <https://doi.org/10.1186/1475-9276-12-14>
- Broniatowski, D. A., Jamison, A. M., Qi, S. H., AlKulaib, L., Chen, T., Benton, A., ... Dredze, M. (2018). Weaponized health communication: Twitter bots and Russian trolls amplify the vaccine debate. *American Journal of Public Health*, 108(10), 1378–1384. <https://doi.org/10.2105/AJPH.2018.304567>
- Budd, J. (2006). Discourse Analysis and the Study of Communication in LIS. *Library Trends*, 55(1), 65–82. <https://doi.org/10.1353/lib.2006.0046>
- Caulfield, T., Marcon, A. R., Murdoch, B., Brown, J. M., Perrault, T., Jerry, J., ... Hyde-
lay, R. (2018). Health Misinformation and the Power of Narrative Messaging in the Public Sphere. *Harvard University*.
- CDC. (2014). Genital HPV Infection – CDC Fact Sheet. *Center of Disease Control and Prevention*, 1–2. <https://doi.org/CS246943B>
- Chew, C., & Eysenbach, G. (2009). Pandemics in the Age of Twitter: Content Analysis of Tweets. *PLoS One*, 5(11), e14118. <https://doi.org/10.1371/journal.pone.0014118>
- Chou, W.-Y. S., Hunt, Y., Folkers, A., & Augustson, E. (2011). Cancer Survivorship in the Age of YouTube and Social Media: A Narrative Analysis. *Journal of Medical Internet Research*, 13(1). <https://doi.org/10.2196/jmir.1569>
- Chou, W. S., Hunt, Y. M., Beckjord, E. B., Moser, R. P., & Hesse, B. W. (2009). Social

- Media Use in the United States: Implications for Health Communication. *Journal of Medical Internet Research*, 11(4). <https://doi.org/10.2196/jmir.1249>
- Colgrove, J., Ph, D., Abiola, S., Mello, M. M., Ph, D., & Carolina, S. (2010). *spe ci a l r e p or t HPV Vaccination Mandates — Lawmaking amid Political and Scientific Controversy*. *New England Journal of Medicine*, 785–791.
- Colineau, N., & Paris, C. (2010). Talking about your health to strangers: Understanding the use of online social networks by patients. *New Review of Hypermedia and Multimedia*, 16(1–2), 141–160. <https://doi.org/10.1080/13614568.2010.496131>
- Collier, R. (2018). Containing health myths in the age of viral Misinformation. *Cmaj*, 190(19), E578. <https://doi.org/10.1503/cmaj.180543>
- Corley, C., Cook, D., Mikler, A., & Singh, K. (2010). Text and Structural Data Mining of Influenza Mentions in Web and Social Media. *International Journal of Environmental Research and Public Health*, 7(2), 596–615. <https://doi.org/10.3390/ijerph7020596>
- Denecke, K., & Nejd, W. (2009). How valuable is medical social media data? Content analysis of the medical web. *Information Sciences*, 179(12), 1870–1880. <https://doi.org/10.1016/j.ins.2009.01.025>
- DiFonzo, N. (2013). Rumour research can douse digital wildfires. *Nature*, 493(7431).
- Dunn, A. G., Leask, J., Zhou, X., Mandl, K. D., & Coiera, E. (2015). Associations between exposure to and expression of negative opinions about human papillomavirus vaccines on social media: An observational study. *Journal of Medical Internet Research*, 17(6), e144. <https://doi.org/10.2196/jmir.4343>
- Dunn, A. G., Surian, D., Leask, J., Dey, A., Mandl, K. D., & Coiera, E. (2017). Mapping

- information exposure on social media to explain differences in HPV vaccine coverage in the United States. *Vaccine*, 35(23), 3033–3040.
<https://doi.org/10.1016/j.vaccine.2017.04.060>
- Ecker, U. K. H., Lewandowsky, S., Fenton, O., & Martin, K. (2014). Do people keep believing because they want to? Preexisting attitudes and the continued influence of misinformation. *Memory and Cognition*, 42(2), 292–304.
<https://doi.org/10.3758/s13421-013-0358-x>
- Farmer, A. D., Bruckner Holt, C. E. M., Cook, M. J., & Hearing, S. D. (2009). Social networking sites: A novel portal for communication. *Postgraduate Medical Journal*, 85(1007), 455–459. <https://doi.org/10.1136/pgmj.2008.074674>
- Fisher, M. C. (2015). Measles , other infectious diseases likely to return without vaccine adherence. *Infectious Diseases in Children*.
- Gyenes, N., & Xiao Mina, A. (2018). How Misinfodemics Spread Disease. *The Atlantic*. Retrieved from <https://www.theatlantic.com/technology/archive/2018/08/how-misinfodemics-spread-disease/568921/>
- Hawkes, N. (2018). HPV vaccines are effective and safe and work best in young women, review finds. *BMJ (Clinical Research Ed.)*, 361(May), k2059.
<https://doi.org/10.1136/BMJ.K2059>
- Hawn, C. (2009). Report from the field: Take two aspirin and tweet me in the morning: How twitter, facebook, and other social media are reshaping health care. *Health Affairs*, 28(2), 361–368. <https://doi.org/10.1377/hlthaff.28.2.361>
- Intlekofer, K. A., Cunningham, M. J., & Caplan, A. L. (2012). The HPV vaccine controversy. *AMA Journal of Ethics*, 14(1), 39–49.

<https://doi.org/10.1001/virtualmentor.2012.14.1.msoc1-1201>

- Kata, A. (2010). A postmodern Pandora's box: Anti-vaccination misinformation on the Internet. *Vaccine*, 28(7), 1709–1716. <https://doi.org/10.1016/j.vaccine.2009.12.022>
- Kim, K., & Kwon, N. (2010). Profile of e-patients: Analysis of their cancer information-seeking from a national survey. *Journal of Health Communication*, 15(7), 712–733. <https://doi.org/10.1080/10810730.2010.514031>
- Kontos, E. Z., Emmons, K. M., Puleo, E., & Viswanath, K. (2010). Communication inequalities and public health implications of adult social networking site use in the United States. *Journal of Health Communication*, 15(SUPPL. 3), 216–235. <https://doi.org/10.1080/10810730.2010.522689>
- Lagu, T., Hannon, N. S., Rothberg, M. B., & Lindenauer, P. K. (2010). Patients' evaluations of health care providers in the era of social networking: An analysis of physician-rating websites. *Journal of General Internal Medicine*, 25(9), 942–946. <https://doi.org/10.1007/s11606-010-1383-0>
- Lariscy, R. W., Reber, B. H., & Paek, H. J. (2010). Examination of media channels and types as health information sources for adolescents: Comparisons for Black/White, Male/Female, Urban/Rural. *Journal of Broadcasting and Electronic Media*, 54(1), 102–120. <https://doi.org/10.1080/08838150903550444>
- Larson, H. J. (2018). The biggest pandemic risk? Viral misinformation. *Nature*, 562(7727), 309–309. <https://doi.org/10.1038/d41586-018-07034-4>
- Lombard, M., Snyder-Duch, J., & Campanella Bracken, C. (2002). Content Analysis in Mass Communication. *Human Communication Research*, 28(4), 587–604. <https://doi.org/10.1111/j.1468-2958.2002.tb00826.x>

- Mahoney, L. M., Tang, T., Ji, K., & Ulrich-Schad, J. (2015). The Digital Distribution of Public Health News Surrounding the Human Papillomavirus Vaccination: A Longitudinal Infodemiology Study. *JMIR Public Health and Surveillance*, 1(1), e2. <https://doi.org/10.2196/publichealth.3310>
- Markowitz, L. E., Gee, J., Chesson, H., & Stokley, S. (2018). Ten Years of Human Papillomavirus Vaccination in the United States. *Academic Pediatrics*, 18(2), S21–S22. <https://doi.org/10.1016/j.acap.2017.09.014>
- Marshall, G. S. (2015). Misinformation , false perception of risk contribute to vaccine hesitancy. *Infectious Diseases in Children*.
- McMillan, S. J. (2000). The microscope and the moving target: The challenge of applying content analysis to the World Wide Web. *Journalism and Mass Communication Quarterly*, 77(1), 80–98. <https://doi.org/10.1177/107769900007700107>
- Moen, A., Smørdal, O., & Sem, I. (2009). Web-based resources for peer support - Opportunities and challenges. *Studies in Health Technology and Informatics*, 150, 302–306. <https://doi.org/10.3233/978-1-60750-044-5-302>
- Moorhead, S. A., Hazlett, D. E., Harrison, L., Carroll, J. K., Irwin, A., & Hoving, C. (2013). A New Dimension of Health Care: Systematic Review of the Uses, Benefits, and Limitations of Social Media for Health Communication. *Journal of Medical Internet Research*, 15(4). <https://doi.org/10.2196/jmir.1933>
- Nordqvist, C., Hanberger, L., Timpka, T., & Nordfeldt, S. (2009). Health professionals' attitudes towards using a web 2.0 portal for child and adolescent diabetes care: Qualitative study. *Journal of Medical Internet Research*, 11(2).

<https://doi.org/10.2196/jmir.1152>

Orenstein, W. A., Douglas, R. G., Rodewald, L. E., & Hinman, A. R. (2005).

Immunizations in the United States: Success, structure, and stress - A complex collaboration involving government, industry, providers, academe, professional societies, and third-party payers. *Health Affairs*, 24(3), 599–610.

<https://doi.org/10.1377/hlthaff.24.3.599>

Phadke, V. K., Bednarczyk, R. A., Salmon, D. A., Omer, S. B., & Health, G. (2016).

Association Between Vaccine Refusal and Vaccine-Preventable Diseases in the United States : A Review of Measles and Pertussis. 315(11), 1149–1158.

<https://doi.org/10.1001/jama.2016.1353.Association>

Russell-Rose, T., & Chamberlain, J. (2017). Expert Search Strategies: The Information

Retrieval Practices of Healthcare Information Professionals. *JMIR Medical Informatics*, 5(4), e33. <https://doi.org/10.2196/medinform.7680>

Salathé, M., & Khandelwal, S. (2011). Assessing Vaccination Sentiments with Online

Social Media: Implications for Infectious Disease Dynamics and Control. *PLoS Comput Biol*, 7(10), e1002199. <https://doi.org/10.1371/journal.pcbi.1002199>

Shelby, A., & Ernst, K. (2013). Story and science: How providers and parents can utilize

storytelling to combat anti-vaccine misinformation. *Human Vaccines and Immunotherapeutics*, 9(8), 1795–1801. <https://doi.org/10.4161/hv.24828>

Smith, T. C. (2017). Vaccine rejection and hesitancy: A review and call to action. *Open*

Forum Infectious Diseases, 4(3), 1–7. <https://doi.org/10.1093/ofid/ofx146>

Southwell, B. G., & Thorson, E. A. (2015). The Prevalence, Consequence, and Remedy

of Misinformation in Mass Media Systems. *Journal of Communication*, Vol. 65, pp.

- 589–595. <https://doi.org/10.1111/jcom.12168>
- Tan, A. S. L., Lee, C., & Chae, J. (2015). Exposure to Health (Mis)Information: Lagged Effects on Young Adults' Health Behaviors and Potential Pathways. *Journal of Communication*, Vol. 65, pp. 674–698. <https://doi.org/10.1111/jcom.12163>
- The Office of Disease Prevention and Health Promotion. (2019). Healthy People 2020. Retrieved from <https://www.healthypeople.gov/2020/topics-objectives/topic/immunization-and-infectious-diseases/objectives>
- Tyring, S. K. (2010). The HPV vaccine controversy: Sex, cancer, God, and politics: A guide for parents, women, men, and teenagers. *Journal of the American Academy of Dermatology*, 63(5), 915–916. <https://doi.org/10.1016/j.jaad.2010.04.032>
- Vogel, L. (2017). Viral misinformation threatens public health. *Canadian Medical Association Journal*, 189(50), E1567–E1567. <https://doi.org/10.1503/cmaj.109-5536>
- Vosoughi, S., Roy, D., & Aral, S. (2018). The Spread of True and False News Online. *Science*, 359(March), 1146–1151. <https://doi.org/10.1126/science.aap9559>
- Vraga, E. K., & Bode, L. (2017). Using Expert Sources to Correct Health Misinformation in Social Media. *Science Communication*, 39(5), 621–645. <https://doi.org/10.1177/1075547017731776>
- Vraga, E. K., & Bode, L. (2018). I do not believe you: how providing a source corrects health misperceptions across social media platforms. *Information Communication and Society*, 21(10), 1337–1353. <https://doi.org/10.1080/1369118X.2017.1313883>
- Weare, C., & Lin, W. (2000). Content Analysis on the World Wide web. *Social Sciences Computer Review*, 18(3), 272–292.
- Webb, H., & Jirotko, M. (2017). Nuance, Societal Dynamics, and Responsibility in

Addressing Misinformation in the Post-Truth Era: Commentary on Lewandowsky, Ecker, and Cook. *Journal of Applied Research in Memory and Cognition*, 6(4), 414–417. <https://doi.org/10.1016/j.jarmac.2017.10.001>

White, M. (2014). Pros, cons, and ethics of HPV vaccine in teens-Why such controversy? *Translational Andrology and Urology*, 3(4), 429–434. <https://doi.org/10.3978/j.issn.2223-4683.2014.11.02>